What is acceptance, and how could it affect health outcomes for people receiving renal dialysis?

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Abstract

Renal dialysis is a life-saving treatment for end-stage renal disease (ESRD) but is burdensome, invasive and expensive. Patients' experiences of dialysis and the outcomes of their treatment could potentially be improved by focusing on 'acceptance'. However, the concept of acceptance has been used in different ways. This article examines ways that acceptance has been conceptualised in research on chronic illness generally and ESRD specifically, and makes proposals for research to understand better what acceptance means for people with ESRD. The aim is to assist the development of acceptance-related measures and interventions to support people with ESRD.

Introduction

Over 28,000 people with end-stage renal disease (ESRD) receive dialysis in the UK, of whom the vast majority (over 25,000) receive hospital-based haemodialysis and a minority (approximately 3,600) receive home-based peritoneal dialysis (McNeil & Ford, 2017). Haemodialysis involves a patient's blood circulating through an extracorporeal circuit to remove uraemic toxins and excess water; treatments generally last four hours and are repeated three times per week. Treatment time is further extended by the time taken either side of the haemodialysis treatment for travel to the hospital and connection to/disconnection from the dialysis machine. Often, patients feel tired or 'lifeless' following a haemodialysis treatment. It is therefore clear that whilst haemodialysis is a treatment that can extend life in the face of ESRD, it places a significant treatment and symptom burden upon patients. Furthermore, patients are subject to a significant increase in overall and cardiovascular mortality (Levy et al., 1996) and experience reduced quality of life (Yusop et al., 2013). Haemodialysis costs over £27,000 per patient per year and consumes 1.3% of all NHS spending (Kerr et al., 2012). It is therefore important to maximise the benefits obtained by dialysis and improve patients' experiences of treatment, and increasing patients' acceptance of their condition and treatment could play a role in this.

Psychological models of acceptance

'Acceptance' can refer to the outcome of an adjustment process, or to the change processes leading to better adjustment. In both cases, 'acceptance' can refer to beliefs, attitudes, emotional states and behaviours like coping and self-management. In models like the 'five stages of grief', acceptance is part of the definition of positive adjustment; people respond to a diagnosis of terminal

illness first with 'denial', then 'anger', 'bargaining', 'depression', and finally 'acceptance' (Kübler-Ross et al., 2014). In other models, acceptance is one of several processes leading to successful adjustment (Moss-Morris, 2013), or is part of an 'ongoing adjustment cycle' (Hammond & Hirst-Winthrop, 2016).

'Acceptance of illness', as measured by the Acceptance of Illness Scale (AIS; Felton & Revenson, 1984), was defined as "a psychological indicator of the quality of adaptation to life with a disease" (Janowski et al., 2013, p. 2), implying it is an outcome. Acceptance of illness scores were associated with health-related quality of life and life satisfaction in several studies (eg., Mroczek, 2017). One cross-sectional study of people with chronic heart failure concluded, through structural equation modelling, that quality of life affected acceptance of illness rather than the other way round (Obieglo et al., 2017). However, among people with a range of chronic illnesses, acceptance of illness was negatively associated with preventative health behaviours, so "higher acceptance of the disease-related burden may be a factor decreasing motivation for preventative actions" (Janowski et al., 2013, p. 7), suggesting that acceptance may have negative effects in some contexts. Based on findings from studies using the AIS, therefore, acceptance of illness could be treated as either an outcome or a process.

'Acceptance of disability', as measured by the Acceptance of Disability Scale (Groomes & Linkowski, 2007), was derived from acceptance of loss theory and ways that people's values change as they accept disability. The changes involve people enlarging the scope of their values, subordinating physical values relative to other values, containing the effects of disability, and focusing on intrinsic rather than comparative values (Wright, 1983). This model emphasises change processes (Keany & Glueckauf, 1993), and acceptance of disability has been associated with improved life satisfaction (Chen & Crewe, 2009) and ways of coping (Groomes & Leahy, 2002).

Acceptance can also be viewed as part of coping, which itself is often included in models of adjustment (e.g. Sharpe & Curran, 2006). One analysis of acceptance as coping distinguished between active acceptance, which was an adaptive response to unchangeable circumstances, and resigned acceptance, which was maladaptive coping associated with negative psychological outcomes (Nakamura & Orth, 2005).

Other models of coping distinguish between appraisal-focused coping, problem-focused coping and emotion-focused coping (Moos & Schaefer, 1984). Acceptance may be a form of appraisal-focused coping, involving accepting the reality of a situation and redefining it as positively acceptable. However, learning to tolerate or accept difficulties and coming to terms with inevitable outcomes is also part of emotion-focused coping, which may be more important than problem-focused coping from the point of view of maintaining psychological wellbeing (Walker et al., 2004).

Coping and cognitive processes are often associated with cognitive behavioural therapy (CBT), which aims to change the content of people's thoughts and beliefs. One CBT intervention for people with rheumatic diseases included acceptance in the form of acknowledging disease, tolerating and managing symptoms, and being willing to engage in meaningful activities. The intervention improved psychological health, and seemed to support a dual-process model of coping, including both assimilative coping (attempting to alter the situation) and accommodative coping (adjusting personal goals) (Vriezekolk et al., 2012).

Acceptance and commitment therapy (ACT) focuses on the context and function of distressing experiences rather than their content. This gives acceptance a more central role, and ACT focuses strongly on values, with interventions that aim to help people focus on aspects of their lives they truly value rather than their difficulties (Hayes et al., 2006). This emphasis on values gives ACT some points of similarity with the concepts behind the Acceptance of Disability Scale (see earlier). ACT interventions have been adapted with some success with the aim of improving quality of life, lifestyle and self-management for people with chronic conditions including cancer, cardiac disease,

type 2 diabetes, epilepsy, multiple sclerosis, cerebral palsy, paediatric brain injury and other life-threatening illnesses. A review of the findings concluded that: “There were some promising data supporting certain applications: parenting of children with long-term conditions, seizure control in epilepsy, psychological flexibility, and possibly disease self-management” (Graham et al., 2016, p. 46).

Chan (2013) suggested that acceptance in ACT has two components; one involving acknowledgement of experiences of illness without engaging in dysfunctional coping, the other involving active integration of the illness into life and pursuing important goals or values. These two components resemble the two aspects of acceptance measured by the Chronic Pain Acceptance Questionnaire; a motivational factor (‘pain willingness’) that involves accepting that trying to avoid or control pain can be counter-productive, and a behavioural factor (‘activity engagement’), which involves continuing with life activities in spite of pain (McCracken et al., 2004).

There is also a technology acceptance model (TEM) that sets out to explain how people accept and use health information technology, which can have important health consequences. This model was originally an adaptation of the theory of reasoned action, and studies of technology acceptance have operationalised the theory of reasoned action and the theory of planned behaviour in different ways, so there are several versions of the model. However, most employ behavioural intention to use the technology in question as the main outcome of interest, and most involve measures of perceived usefulness and perceived ease of use as key attitudinal predictors of behavioural intention (Holden & Karsh, 2010). The TEM has mainly been used with health care professionals, but technology acceptance also predicted patients’ acceptance of internet-based health technology (Wilson & Lankton, 2004).

Psychological models of acceptance therefore include change process models, psychometric models, theoretical conceptualisations, and models based on the processes targeted by treatment interventions. The range of different psychological approaches to acceptance shows what a multifaceted concept acceptance is, and how it can be defined in different ways depending on the context.

Acceptance in ESRD research

Acceptance in different forms has begun to feature in qualitative and quantitative research in people with ESRD, but to date the scope of this is limited. There is no consensus about what acceptance means in the context of ESRD, or how acceptance is related to other factors, especially treatment outcomes and patient wellbeing and adjustment.

One interview study showed that ESRD patients recognised the importance of acceptance and were receptive to research aiming to understand and improve acceptance (Schipper & Abma, 2011). Other interview studies of dialysis patients identified aspects of acceptance as part of coping (de Guzman et al., 2009), especially coping with stress (Gurklis & Menke, 1995). Interviews with peritoneal dialysis patients and their partners/carers distinguished between ‘active’ versus ‘resigned’ acceptance (Wright & Kirby, 1999). A meta-synthesis of qualitative findings about the experiences of haemodialysis patients identified a theme that related acceptance to the development of “a new dialysis-dependant self”. This combined two different types of acceptance, and the authors suggested that for some patients acceptance could reflect a perception of dialysis as a life-sustaining gift, whereas for others it could reflect resignation and a realisation that there was no alternative to dialysis (Reid et al., 2016).

One cross-sectional questionnaire study of ESRD patients showed that acceptance of illness was higher among those who received transplants than those on dialysis, and also higher among patients who were in employment. One interpretation was that patients associate transplantation with greater choice and independence, including greater opportunity to work, and it is this

perception of choice, plus the psychological benefits of being in employment, that leads to greater acceptance of illness (Keogh & Feehally, 1999).

A study of people with chronic kidney disease showed that greater acceptance of disability was associated with having more education and less severe kidney disease, which might be factors that influence acceptance, but also with taking more exercise and sleeping better, which might be among the effects of greater acceptance (Chiang et al., 2015). Among patients receiving haemodialysis, acceptance of disability was related to internal locus of control (Poll & De-Nour, 1980).

A study of haemodialysis patients that measured acceptance as part of the COPE inventory found that acceptance was related to cognitive reappraisal of stress and positive reframing, suggesting it could be a precursor to adaptive coping (Gillanders et al., 2008). One study of chronic kidney disease that measured acceptance as 'accommodative coping' found that this predicted physical and mental quality of life, and mediated the effects of neuroticism on mental quality of life (Poppe et al., 2013). A further study assessed acceptance of fluid restrictions among dialysis patients and found that this was related to age, gender and general health (Silva et al., 2014). A longitudinal study of ESRD patients that measured acceptance in terms of attributions for the problems caused by ESRD and its treatment found that high acceptance of responsibility and low self-blame predicted better emotional adjustment at 6-month follow-up (Rich et al., 1999).

In another longitudinal study, chronic kidney disease patients with low acceptance of disability were more likely to have progressed to dialysis at 3-year follow-up (Chiang et al., 2015). One proposed explanation was that low disability acceptance is associated with treatment non-adherence and diet and exercise behaviours that can accelerate disease progression. Another was that distressed mood associated with low acceptance could lead to systematic inflammation and immunosuppression, which can worsen illness prognosis and increase risk of infection and mortality.

Chiang et al. (2015) treated acceptance of disability very simplistically as an indicator of negative mood, with no reference to the change processes involved in the original concept of acceptance of disability. However, their first proposed explanation suggests that acceptance influences outcomes via a behavioural pathway, with acceptance part of a behavioural process related to coping and self-management, whereas the other suggests a psychosomatic pathway. This may be similar to the dual role proposed for the influence of 'optimism' on health outcomes, which involved direct effects of optimism on the neuroendocrine and immune responses, and indirect effects on other health outcomes via coping strategies, protective health behaviours and enhanced positive mood (Avvenuti et al., 2016).

One ACT-based intervention reduced pain catastrophizing among haemodialysis patients (Ramezanzadeh & Manshaee, 2016), but another that focused on reducing depression among haemodialysis patients found that illness and treatment factors contributed to poor intervention engagement (Vogt et al., 2016). Acceptance of treatment may be especially important in ESRD because dialysis is such an invasive, burdensome treatment for patients. Considerable effort is focused on tailoring dialysis treatment and adapting dialysis to reduce its negative impact on patients (eg., Selby et al., 2006), but the benefits of technical improvements in dialysis may depend on how patients engage with them, so aspects of acceptance of treatment and acceptance of technology might be expected to affect adherence and treatment outcome.

Patients often belief that acceptance of illness is important in ESRD (eg., Shipper & Abmer, 2011), but research evidence supporting the role of acceptance in ESRD is varied. What is evident is that acceptance has been associated with both processes and outcomes related to adjustment to illness. The evidence suggests relationships between acceptance and a range of clinical, demographic and psychological measures. What needs further investigation is how acceptance affects these outcomes; for example, does acceptance exert a key influence, or is it one of many

influences, or is it a mediator of other influences? Understanding more about the process of acceptance within the ESRD population will allow the development, selection and application of acceptance-based interventions derived from the most appropriate models of acceptance.

Ways forward for acceptance research in ESRD

Acceptance concepts need to be translated for specific conditions and treatments with great care, for acceptance has multiple understandings and interpretations (Risdon et al., 2003). From the interview studies described above, acceptance seems to be viewed by ESRD patients mainly as an aspect of coping, but more needs to be known about the forms of acceptance that represent functional and adaptive coping in relation to dialysis, and the forms that could affect wellbeing and psychological adjustment independently of coping and self-management. Better evidence about that could inform the adaptation of ACT-based acceptance approaches for people with ESRD. It is possible also that important aspects of acceptance change over the course of treatment as patients and their illness progress from diagnosis to different forms of treatment. The existing evidence poses a number of questions about acceptance in ESRD, including:

1. What does acceptance mean for people with ESRD, and how does the meaning of acceptance change for them as they progress from diagnosis to dialysis initiation then maintenance, and in some cases transplantation?
2. What are the distinctive ways in which acceptance of ESRD differs from more generic forms of acceptance, like those represented by standardised scales?
3. How does acceptance influence psychological and physical outcomes for people with ESRD, and to what extent is that influence mediated by behavioural and/or psychosomatic factors?
4. To what extent is acceptance a worthwhile target for interventions; how far can it change, and in response to what influences?
5. How does acceptance influence how people respond to dialysis and other treatments that are increasingly technological?

To conclude, acceptance provides a very useful theoretical framework for initiatives that may help patients achieve better adjustment to dialysis and maximize the benefits they obtain from dialysis. However, a number of different acceptance-related models and constructs are available, and research is needed to identify which aspects of acceptance are most relevant in the context of ESRD, and what acceptance means for patients receiving renal dialysis. The next step could then be to develop and evaluate acceptance-based interventions that are based on the most relevant forms of acceptance and are specifically adapted for patients with ESRD treated by renal dialysis.

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